



Intellectual & Developmental Disabilities in Georgia:

Statistics, Services & Recommendations for Improvement

2022 Fall Senate Study Committee on People with Intellectual and Developmental
Disabilities and Waiver Plan Access

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GCDD, Defining DD, and Waiver Criteria



GCDD's Mission

The mission of the Georgia Council on Developmental Disabilities is to bring about social and policy changes that promote opportunities for the wide spectrum of persons/people with developmental disabilities and their families to live, learn, work, play, and worship in their communities.



About GCDD

- GCDD is a federally funded, self-governing organization charged with identifying the most pressing needs of people with developmental disabilities in Georgia.
- As per the federal Developmental Disabilities Assistance and Bill of Rights Act (DD Act), over 60% of our members must be individuals with developmental disabilities or their family members.



The DD Act's Definition of Developmental Disability

A severe, chronic disability of an individual that—

- (i) is attributable to a **mental or physical impairment or combination** of mental and physical impairments;
- (ii) is manifested before the individual attains **age 22**;
- (iii) is likely to continue **indefinitely**;
- (iv) results in **substantial functional limitations** in 3 or more of the following areas of major life activity:

- | | | | |
|--------------------|---------------------------------------|-------------------------------|--------------|
| (a) Self-care | (b) Receptive and expressive language | (c) learning | (d) mobility |
| (e) self-direction | (f) capacity for independent living | (g) economic self sufficiency | |

and

- (h) reflects the individual's need for a combination and sequence of special, interdisciplinary, or generic **services, individualized supports, or other forms of assistance that are of lifelong or extended duration and are individually planned and coordinated.**



NOW/COMP Waiver Eligibility Definition

Eligibility through diagnosis of an **intellectual disability** is defined by the following three criteria:

- (1) Age of Onset: Onset before the age of **18 years**;
- (2) Significantly Impaired Adaptive Functioning: **Significant limitations in adaptive functioning** (as defined by the testing instrument but typically at least two standard deviations below the mean), as measured by an overall domain composite score in at least one of the following skill areas: **conceptual skills** (e.g., language; reading and writing; and money, time, and number concepts); **social skills** (e.g., interpersonal skills, social responsibility, self-esteem, gullibility, naiveté or wariness, follow rules/obeys laws, avoids being victimized, and social problem solving; and **practical skills** (e.g., activities of daily living or personal care, occupational skills, use of money, safety, health care, travel/transportation, schedules/routines, and use of the telephone) OR an overall score on a standardized measure of conceptual, social, and practical skills; and



NOW/COMP Waiver Eligibility Definition Cont.

(3) Significantly Sub-average General Intellectual Functioning: [Significantly sub-average general intellectual functioning defined as an intelligence quotient \(IQ\) of about 70 or below](#) (approximately two standard deviations below the mean). Individuals with an IQ of 70 to 75 with appropriately measured, significant impairments to adaptive behavior that directly relate to issues of an intellectual disability may be considered as having an intellectual disability. Findings of the significant limitations in adaptive functioning and general intellectual functioning must be consistent with a diagnosis of intellectual disability and not solely the result of mental/emotional disorders, neurocognitive disorders, sensory impairments, substance abuse, personality disorder, specific learning disability, or attention-deficit/hyperactivity disorder.

Eligibility through a “[Related Condition](#)” is defined as having a diagnosis of a [condition found to be closely related to an intellectual disability](#) and attributable to:

- (a) [severe forms of autism, cerebral palsy, or epilepsy](#); or
- (b) any other condition found to be closely related to an intellectual disability because the closely related condition results in significant impairment of general intellectual functioning (defined as an intelligence quotient of about 70 or below-approximately two standard deviations below the mean) or adaptive behavior due to an impact of the condition on brain functioning that results in adaptive behavior impairments which are similar to that of individuals with an intellectual disability. [To be a closely related condition, the condition must impact the individual in such a way that the individual requires treatment or services similar to those required for individuals with intellectual disability.](#)



NOW/COMP Waiver Eligibility Definition Cont.

Additionally, the following criteria must be met:

- (1) The individual must experience onset of the related condition and associated substantial adaptive functioning deficits before the age of [22 years](#);
- (2) The individual requires an [ICF/ID level of care without home and community-based treatment or services](#) similar to those required for individuals with a diagnosis of an intellectual disability;
- (3) The individual exhibits [limitations in adaptive functioning](#) (as defined by the testing instrument but typically at least two standard deviations below the mean) in three or more of the following areas of functioning: self-care, receptive and expressive language, learning, mobility, self-direction, and capacity for independent living; and the adaptive impairments must be directly related to the developmental disability and cannot be primarily attributed to solely physical conditions, neuromuscular disorders, dementia, mental/emotional disorders, borderline intellectual functioning, sensory impairments, substance abuse, personality disorder, specific learning disability, communication or language disorders, or attention deficit/hyperactivity disorder; and
- (4) The disability results in current [substantial deficits in intellectual functioning or in three or more of the specified areas of adaptive behavior or functioning and is likely to continue indefinitely](#).



ID/DD Statistics & Services



Georgians with ID/DD

- Prevalence rate study¹ shows Georgians with ID/DD make up approximately 1.58% of the population or about **170,640 Georgians**
- However, more recent State of the States² shows there are approximately **226,000 caregiving families** supporting someone with ID/DD in Georgia

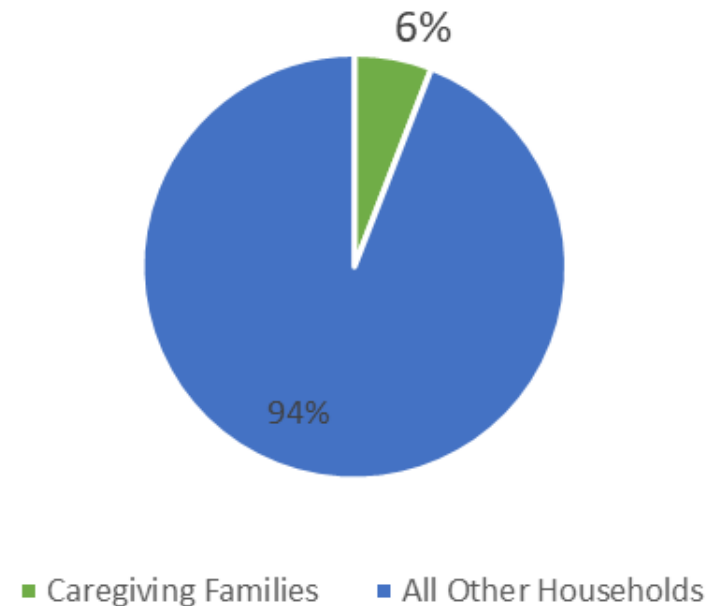
1. 1994–1995 National Health Interview Survey on Disability (NHIS-D)

2. Tanis, E.S., et al. (2022). The State of the States in Intellectual and Developmental Disabilities, Kansas University Center on Developmental Disabilities, The University of Kansas.

Georgians with ID/DD

- State of the States² shows there are approximately **226,000 caregiving families** supporting someone with ID/DD in Georgia
- Most recent US Census shows there are **3,830,264 total households** in Georgia

Approximate Percentage of Georgia Families
Caregiving for Individual with ID/DD



1. 1994–1995 National Health Interview Survey on Disability (NHIS-D)

2. Tanis, E.S., et al. (2022). The State of the States in Intellectual and Developmental Disabilities, Kansas University Center on Developmental Disabilities, The University of Kansas.

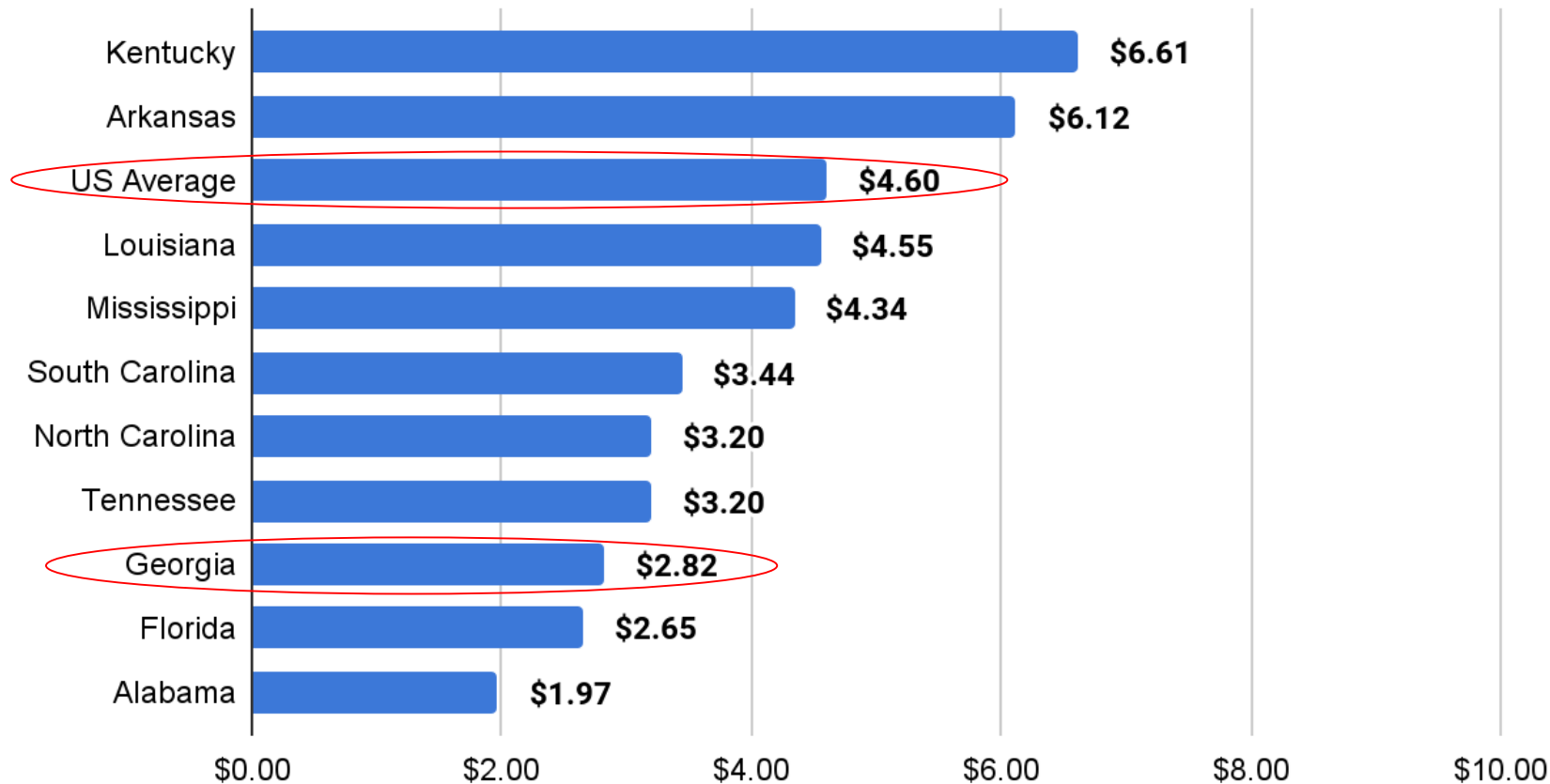


NOW/COMP Numbers

- As of August - 13,061 Georgians were receiving NOW/COMP waivers
- As of August - 7,155 were on the waiting list

Georgia ID/DD Fiscal Effort

FY19 Fiscal Effort by States in Southeast Region



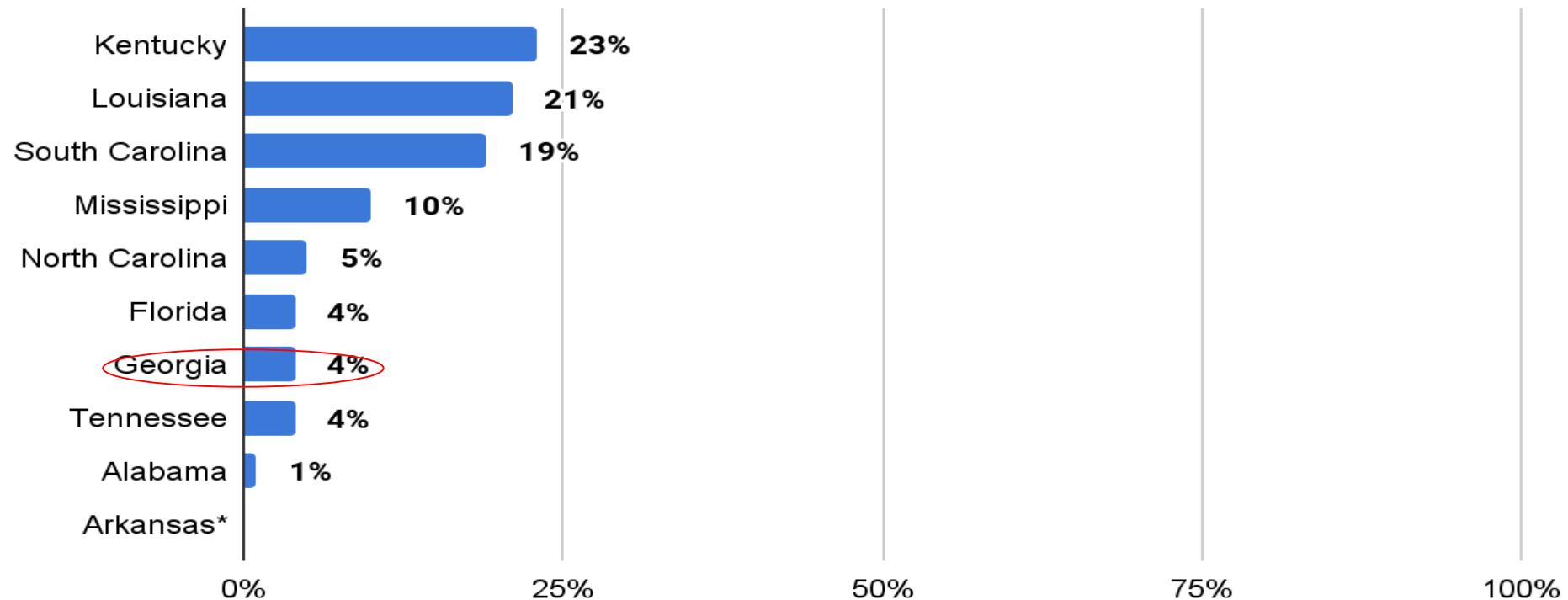
Fiscal Effort is defined as spending per \$1,000 of personal income.

Fiscal Effort allows for comparison of states' spending.

Source: Tanis, E.S., et al. (2022). The State of the States in Intellectual and Developmental Disabilities, Kansas University Center on Developmental Disabilities, The University of Kansas. <http://www.StateoftheStates.org>

Georgians with ID/DD

FY19 Estimates of Caregiving Families and the % of Those Families Receiving State Support



Source: Tanis, E.S., et al. (2022). The State of the States in Intellectual and Developmental Disabilities, Kansas University Center on Developmental Disabilities, The University of Kansas. <http://www.StateoftheStates.org>

Who's Paying?



Georgia Families



Georgia Businesses



Georgians with ID/DD

Who's Paying?



**“Families have to break before they can get support.
And usually in a way that hurts the person with disabilities.”**

-Provider



Ideas & Recommendations

Why reconsider? Economic Argument



**Boost family
stability - obtain
& advance
employment**



**Add & retain
employees, give back
to local economy**



**Contribute to
communities,
particularly under
Employment First**

Waivers Benefit Economy

- Recent study found HCBS waivers benefit state and federal economy by reducing unmet healthcare needs and allowing families to continue working.¹
- Estimated national caregiving costs to businesses is \$33.6 billion.²
 - Resulting from issues like replacing employees, absenteeism, unpaid leave, and other issues resulting from unpaid family caregiving

1. McLean KJ, Hoekstra AM, Bishop L. United States Medicaid home and community-based services for people with intellectual and developmental disabilities: A scoping review. J Appl Res Intellect Disabil. 2021 May;34(3):684-694. doi: 10.1111/jar.12837. Epub 2020 Nov 28. PMID: 33247520; PMCID: PMC8058309.

2. MetLife Mature Market Institute and NAC. The MetLife Caregiving Cost Study: Productivity losses to U.S. business. Westport, CT: MetLife Mature Market Institute and NAC; 2006

Waivers Benefit Economy

- From Advancing Employment: Employment services for people with ID/DD benefit economy:
 - For every \$1 spent, there is a \$1.46 return
 - There is an average monthly net benefit of \$251 to taxpayers per supported employee
 - There is an average annual net benefit of \$3,016 to taxpayers per supported employee

Source: Cimera, R. E. (2009). Supported Employment's Cost-Efficiency to Taxpayers: 2002 to 2007. *Research and Practice for Persons with Severe Disabilities*, 34(2), 13–20. <https://doi.org/10.2511/rpsd.34.2.13>

Recent Examples of State Investments

- Examples of states that appropriated enough funds to end their waitlist:
 - Arkansas: December 2021 Governor Asa Hutchinson announced his administration would end the waitlist (3200 at the time), and the general assembly approved the Governor's \$37.6 million to fund the new waiver slots in 2022 session
 - Oklahoma: in 2022 the state appropriated ~\$32 million to fund the entire waitlist (about 5,200), which totaled a \$174 million dollar investment after federal match



Recent Examples of State Investments Cont

- State investments targeting higher waiver slots:
 - Florida appropriated about \$95 million in 2021 to fund 1,900 waiver slots and \$59.6 million in 2022 to target moving 1,100 people off the waitlist



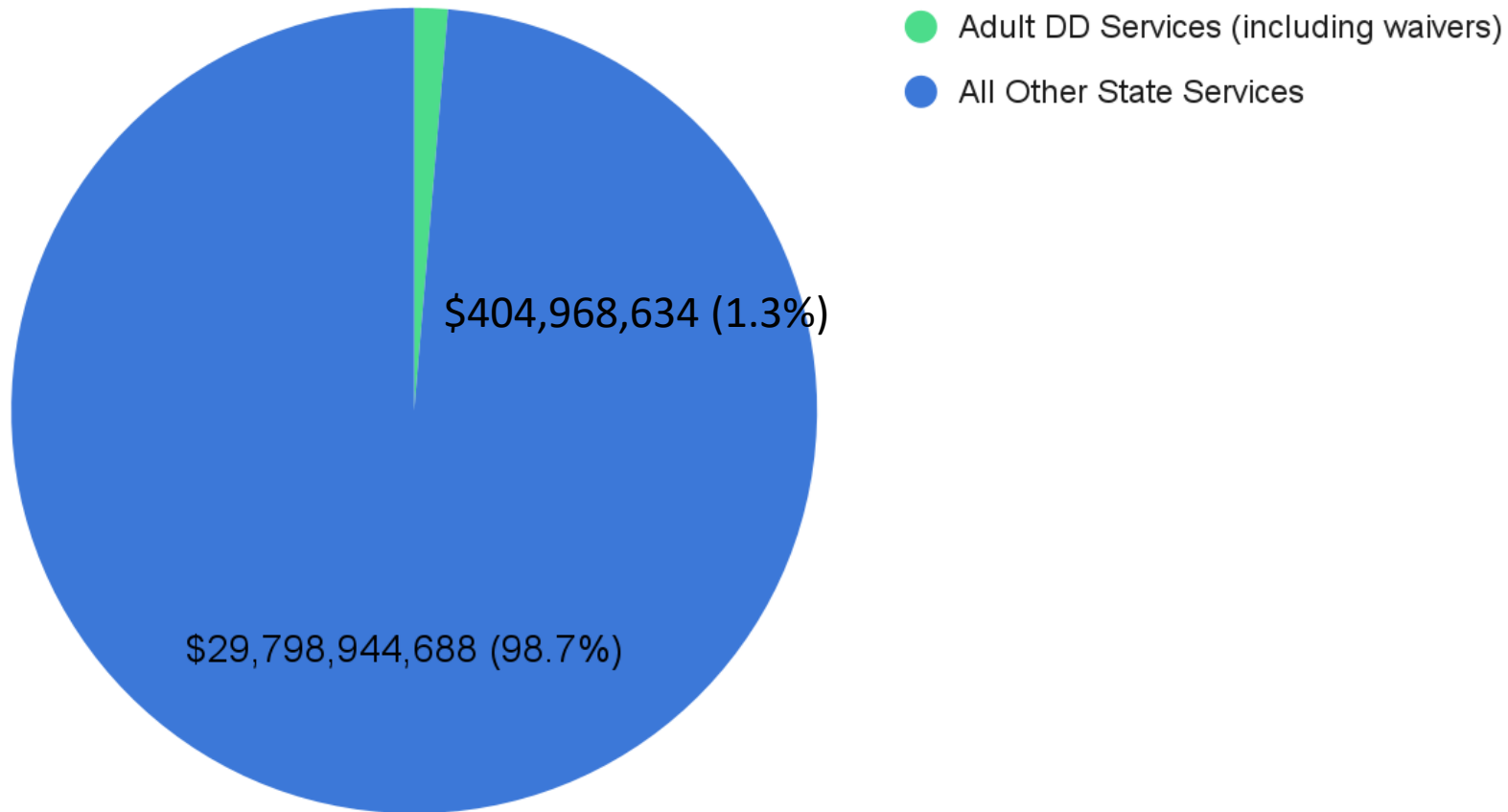
Recent Examples of State Investments Cont

- Southeast states using ARPA funds to reduce waiver waiting lists:
 - Alabama
 - Florida
 - Mississippi
 - North Carolina
 - Tennessee

Source: <https://www.ancor.org/connections/wait-list-management-american-rescue-plan-act-2021-funding-update/>

Georgia Can Invest

Adult DD Services Appropriations in FY23 Budget





Georgia Can Invest

Consider 2023 refunds

- In 2022, Georgia gave \$1.1 billion in tax refunds (\$250 per person)
- A \$25 reduction per person could have funded ~5,500 new waiver slots

Current \$6.6 billion dollar surplus will need to be spent

- 0.3% of this total could be put toward funding 1,000 new waiver slots

Georgia spends ~\$54 million per year for GNETS

- reduction in GNETS funding could be directed toward annualizing NOW/COMP waivers

Short-Term Advocacy & Strategies

- 2023 Georgia General Assembly Session:
 - 1,000 new NOW/COMP waiver slots ~ \$19.8 million
 - Funding to increase DSP wages to minimum of \$15 per hour
 - Update long-term DD services plan, complete with benchmarks & funding strategies



Medium to Long-Term Advocacy & Strategies

1. End the wait list - fully fund NOW/COMP wait list and maintain focus of ongoing waiver needs
2. Keep DSP's at a livable wage to support GA families & businesses
 - a. Participate in national conversation & strategies around DSP workforce
3. Centralize Employment 1st in waivers & services
4. Work to maximize resources in a way that supports individuals with disabilities & families
 - a. GVRA gives back federal \$
 - b. Georgia % of state spending vs Medicaid spending is high
5. Consider potential Medicaid care model changes with great diligence
6. Develop long-term, person- and family-centric service evaluation model to ensure HCBS services are appropriate and meaningful for Georgians with ID/DD and their families



Thank you! Questions?

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www.gcdd.org



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